

# DEPARTMENT OF COMMUNITY AND HUMAN SERVICES DEVELOPMENTAL DISABILITIES DIVISION

July 1, 2005 – June 30, 2009 Plan for Developmental Disabilities Services

Developed in collaboration with Washington State Division of Developmental Disabilities Region 4

Approved by:

The King County Board for Development Disabilities on June 15, 2005

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King County Plan for Developmental Disabilities Services Revision Date: 7/1/05

# **Table of Contents**

Chapter 1 - Introduction4
Chapter 2 - Overview of Developmental Disabilities8
Table 1: Estimated Percent of U.S. Population with Developmental Disabilities by Age Group13
Table 2: Functional Limitations14
Chapter 3 - Supports Provided by DDD and KCDDD20
Table 3: KCDDD Revenue Summary 2001-200527
Table 4: KCDDD Expenditure Summary 2001-200428
Table 5: KCDDD Expenditure Detail for 2003-200528
Chapter 4 - Issues33
Table 6: Individuals Ages 21-61 Enrolled in DDD Region 4 by Waiver Status and Participation in Day Programs/Employment Supports on January 31, 2005
Table 7: Individuals Age 35+ Enrolled in Region 4 DDD and Living in Parent's Home on January 31, 200536
Table 8: Enrollment in Region 4 DDD by Age Group, Ethnicity and Hispanic Origin on January 31, 200538
Table 9: Enrollment in KCDDD Day Programs by Age Group and Ethnicity on January 31, 200538
Chapter 5 - Goals, Objectives, and Strategies40
Appendices
Appendix A: Focus Group Report
Appendix B: Summary of Demographic and Service Data
Appendix C: Summary of Reports and Plans Regarding Services for People with Developmental Disabilities in King County
Appendix D: Comments on Public Review Draft

# **Chapter 1 - Introduction**

## Purpose of this Plan

The King County Plan for Developmental Disabilities Services ("The Plan") will guide County funded services for individuals with developmental disabilities over the next two State biennia: July 1, 2005 through June 30, 2007 and July 1, 2007 through June 30, 2009.

The Plan identifies issues affecting services for individuals with developmental disabilities as well as children with developmental delays in King County. In addition, the plan identifies goals, objectives and strategies that the King County Developmental Disabilities Division (KCDDD) will implement to address these issues between 2005 and 2009. The goals, objectives and strategies will guide how KCDDD uses available resources to carry out its mission as well as provide a framework for measuring performance.

The Plan meets a State planning requirement. County governments and developmental disability boards that seek State funding to provide local services for people with developmental disabilities and their families are required by State law (RCW 71A.14.030) and regulations (WAC 388-850-020) to submit a plan for approval by the Secretary of the Department of Social and Health Services. The plan must cover the State fiscal biennium and be consistent with County Guidelines published by Washington State Department of Social and Health Services, Division of Developmental Disabilities (DDD) in July 1992.

#### Mission

KCDDD's mission is to assist King County residents of all ages and cultures who have developmental disabilities to achieve full, active, integrated and productive participation in community life.

#### Vision

The vision that is the focus of KCDDD's work is that all individuals with developmental disabilities residing in King County will have the opportunity to realize their life goals as full participants in their communities.

#### Core Values

The core values that guide how the KCDDD carries out its mission are:

Value: Inclusion of people with developmental disabilities in all aspects of community life.

 People with developmental disabilities participate in ageappropriate activities with typically developing peers. Public and private sector organizations encourage inclusion of people with disabilities in their activities. Value: Respect for individuals with developmental disabilities and their families.

 People with developmental disabilities are treated with dignity and as equals. The process for planning supports is person and family centered and culturally relevant. People first language is used. People with developmental disabilities and their families exercise power and choice in decision-making. Agencies that provide supports provide information that is timely, accurate and accessible. Agencies also regularly seek input from people with developmental disabilities and their families on issues that affect them.

Value: Expertise and commitment of support providers.

 Support providers are paid living wages, have opportunities for professional development and advancement and are recognized for contributions to their field. Funders provide information that is timely, accurate and accessible. Agencies also regularly seek input from support providers on issues that affect them.

Value: Accountability for use of public resources.

 The public, including people with developmental disabilities and their families, have up to date information on how funds are used.

Value: Effective and evidence-based practices.

 Funders, families, and support providers share their knowledge about effective and evidence-based practices. Services and supports are provided in a manner consistent with effective and evidence-based practices.

What is People First Language?

People First Language puts the person before the disability: "People with developmental disabilities" rather than "the developmentally disabled."

Who are support providers?

Support providers are individuals who are paid to assist individuals with developmental disabilities to live in the community and participate in community life. They include family resource coordinators, residential program staff, personal care workers, job coaches and other professionals and paraprofessionals.

What are effective and evidence-based practices?

Effective practices are methods of providing services that have been evaluated and shown to result in intended outcomes in a particular setting. Evidence-based practices (sometimes also called "best practices") are methods of providing services that have been evaluated and shown to result in intended outcomes when replicated in a variety of settings.

## **How the Plan was Developed**

The Plan was developed by KCDDD staff and the King County Board for Developmental Disabilities between September 2004 and March 2005. KCDDD staff compiled data to identify critical system issues and needs including:

- Sponsoring a series of 13 focus groups involving 68 community members (the Report on King County Planning Focus Groups is Appendix A;)
- Analyzing demographic and service data from the DDD Common Client Database and the Infant, Toddler, Early Intervention Program Database (the summary of data is Appendix B;)
- Reviewing findings and recommendations in recent reports and plans about services for individuals with developmental disabilities in King County (See Appendix C for summary of reports and plans.)

KCDDD staff and the Board analyzed the data and identified key issues as well as proposed goals, objectives and strategies for addressing those issues.

A draft plan was made available for public review on the KCDDD web site on April 1, 2005. Information regarding how to obtain the draft document and comment was e-posted on the web site, mailed and e-mailed to organizations and individuals on KCDDD's mailing list. The public was invited to submit comments by:

- completing an on-line comment form on the KCDDD web site;
- mailing or delivering written comments to KCDDD;
- attending public meetings held:

April 6, 2005, from 9:30 to 11:30 a.m. at a regular meeting of the King County Board for Developmental Disabilities at the DDD, Region 4 offices in Seattle;

April 19, 2005, from 6:00 to 8:00 p.m. at the Federal Way Regional Library in Federal Way;

April 26, 2005, from 6:00 to 8:00 p.m. at the Highland Community Center in Bellevue; and

April 30, 2005, from 11:30 a.m. to 1:00 p.m. at the Third Place Commons in Lake Forest Park

A press release from King County with information on how to obtain and comment on the draft plan was distributed to regional media on April 1, 2005.

Public comments were reviewed and the draft plan was revised in consideration of the feedback received. The final plan was approved by a motion of the King County Board for Developmental Disabilities on June 15, 2005.

## Monitoring the Plan

The Plan will be reviewed by KCDDD and the King County Board for Developmental Disabilities and updated on an annual basis. KCDDD will annually monitor and report progress on goals, objectives, and strategies.

## **How the Plan is Organized**

Chapter 2 provides an overview of developmental disabilities and developmental delays, how individuals are affected and how supports enable individuals with developmental disabilities to participate in their communities.

Chapter 3 describes the responsibilities of DDD and KCDDD in providing supports for people with developmental disabilities and their families.

Chapter 4 describes the key issues that KCDDD will focus on over the next four year period.

Chapter 5 identifies the goals, objectives and strategies that KCDDD will use to address the key issues as well as recommended actions for DDD.

King County Plan for Developmental Disabilities Services Revision Date: 7/1/05

# **Chapter 2 - Overview of Developmental Disabilities**

## What are developmental disabilities?

Developmental disabilities are severe physical and/or mental impairments that occur before adulthood, are permanent and limit an individual's ability to function. The definition of developmental disability originated in a 1970 federal law, the first of several that provide funding for services and establishes the rights of people with developmental disabilities.<sup>1</sup>

The current federal definition of developmental disability was adopted in 2000:<sup>2</sup>

- (A) In general, a severe, chronic disability of an individual that—
- (i) Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (ii) Is manifested before the individual attains age 22;
- (iii) Is likely to continue indefinitely;
- (iv) Results in substantial functional limitations in three or more of the following areas of major life activity:
  - (I) Self-care;
  - (II) Receptive and expressive language;
  - (III) Learning;
  - (IV) Mobility;
  - (V) Self-direction;
  - (VI) Capacity for independent living; and
  - (VII) Economic self-sufficiency
- (v) Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.
- (B) Infants and young children
  An individual from birth to age 9, inclusive, who has a substantial

<sup>&</sup>lt;sup>1</sup> Developmental Disabilities Services and Facilities Construction Amendments of 1970, PL 91-517, Section 102 (a), 84 Stat. 1325.

<sup>&</sup>lt;sup>2</sup> Developmental Disabilities Assistance and Bill of Rights Act of 2000, PL 106-402, Section 102 (8,) codified at 42 United States Code 15002 (8.) Note the criteria in section A of the definition were originally adopted in the Rehabilitation Comprehensive Services and Developmental Disabilities Amendments of 1978, PL 95-602, 92 Stat. 3004.

developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting three or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life

Washington State's current definition of developmental disability, which is used to determine eligibility for State services, was adopted in 1982 and mirrors the original federal definition from 1970.<sup>3</sup>

"Developmental disability" means a disability attributable to mental retardation, cerebral palsy, epilepsy, autism, or another neurological or other condition of an individual found by the secretary to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation, which disability originates before the individual attains age eighteen, which has continued or can be expected to continue indefinitely, and which constitutes a substantial handicap to the individual.

## What conditions cause developmental disabilities?

Medically diagnosed conditions alone do not determine whether an individual has a developmental disability but rather an individual's functional limitations and need for supports. A wide range of conditions that occur before adulthood can result in a person having functional limitations. An individual may have one or more conditions. Examples of conditions that cause the type of functional limitations experienced by people with developmental disabilities include:

Autism Spectrum Disorders, also referred to as Pervasive Development Disorders, include Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, Rett's Disorder, and Pervasive Development Disorder – Not Otherwise Specified. Symptoms include impaired social interaction, problems with verbal and nonverbal communication and imagination, and unusual or severely limited activities and interests. The most severe cases of autism are marked by extremely repetitive, unusual, self-injurious, and aggressive behavior. The mildest forms of autism resemble a personality disorder associated with a perceived learning disability.<sup>4</sup>

<sup>&</sup>lt;sup>3</sup> Washington State Laws 1982, Chapter 224, as amended by Washington State Laws 1988, Chapter 176, codified at Revised Code of Washington 71A 10.020 (3.) See also Washington Administrative Code 388-823-0040, effective July 5, 2005.

<sup>&</sup>lt;sup>4</sup> Gosden, S., Accommodations for People with Mental Retardation or Other Developmental Disabilities, US Department of Labor, Office of Disability Employment Policy, Job Accommodation Network; available on-line at: http://www.jan.wvu/edu/media/MR.html; See also Graziano, A. (2002.) Developmental Disabilities: Introduction to a Diverse Field, Boston: Allyn and Bacon, chapter 11.

The estimated prevalence rate for autism is .40 per 1,000 people.<sup>5</sup> Recent studies have estimated the prevalence rate for autism in children between 3.4 and 6.7 per 1,000.<sup>6</sup> An estimated 80% of people with autism have functional limitations that meet the federal definition of developmental disability.<sup>7</sup>

<u>Cerebral Palsy</u> is caused by brain damage, affecting ability to control movement and posture. People with Cerebral Palsy exhibit muscle weakness (paresis,) inability to make voluntary movements and suppress involuntary ones. It can be associated with other problems such as seizures, mental retardation, ear/hearing problems, eye/vision problems, or verbal communication problems.<sup>8</sup>

The estimated prevalence rate for cerebral palsy is 4.02 per 1,000 people. An estimated 22% of people with cerebral palsy have functional limitations that meet the federal definition of developmental disability. <sup>9</sup>

Mental Retardation, sometimes referred to as Intellectual Disability, begins in childhood and is characterized by limitations in both intelligence and adaptive skills such as communication and self-care. An individual is considered to have mental retardation based on three criteria: intellectual functioning level (IQ) is below 70-75; significant limitations exist in two or more adaptive skill areas; and the condition is present from childhood (defined as age 18 or less.)<sup>10</sup>

<sup>&</sup>lt;sup>5</sup> This rate is estimated for people of all ages. Larson, S., Lakin, K.C., Anderson, L., Kwak, N., Lee, J.H., and Anderson, D. (2001.) Prevalence of Mental Retardation and Developmental Disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation*, 106, pp. 248.

<sup>&</sup>lt;sup>6</sup> Bertrand, J. et.al (2001.) Prevalence of Autism in a United States Population: The Brick Township, New Jersey Investigation. *Pediatrics*, 108, pp. 1155-1161 [found rate of 6.7 per 1,000 children ages 3 to 10;] Gurney, J.G., et. al (2003.) Analysis of Prevalence Trends of Autism Spectrum Disorder in Minnesota. *Archives of Pediatric Adolescent Medicine*, 157, pp. 622-627 [found rate of 5.2 per 1,000 children ages 6 to 11;] and Yeargin-Allsopp, M., et. al (2003.) Prevalence of Autism in a US Metropolitan Area. *Journal of the American Medical Association*, 289, pp. 49-55 [found rate of 3.4 per 1,000 children ages 3 to 10.] Data suggest that autism prevalence has been increasing with time although the increase may be slowing. See Newschaffer, C.J., et. al (2005.) National Autism Prevalence Trends from United States Special Education Data. *Pediatrics*, 115, pp. 277-282.

<sup>&</sup>lt;sup>7</sup> Larson, et al. p. 248.

<sup>&</sup>lt;sup>8</sup> Gosden; see also Graziano, Chapter 13.

<sup>&</sup>lt;sup>9</sup> Larson, et. al, p. 248.

<sup>&</sup>lt;sup>10</sup> Gosden; See also Graziano, Chapter 9; see also American Association on Mental Retardation 2002 definition of mental retardation, available on-line at: http://www.aamr.org/Policies/fag\_mental\_retardation.shtml.

The estimated prevalence rate for mental retardation is 7.80 per 1,000 people. An estimated 28% of people with mental retardation have functional limitations that meet the federal definition of developmental disability. <sup>11</sup>

<u>Spina Bifida</u> is characterized by a defective closure in the vertebral column. The most common impairment is partial or total paralysis of affected muscle groups. People with spina bifida may also have bowel and bladder dysfunction. Individuals may develop hydrocephalus, which can create learning disabilities and other cognitive impairments.<sup>12</sup>

The estimated prevalence rate for spina bifida is .62 per 1,000 people. An estimated 20% of people with spina bifida have functional limitations that meet the federal definition of developmental disability. 13

Disorders occurring before birth that can cause conditions resulting in a developmental disability include. <sup>14</sup>

- genetic defects which can cause congenital birth defects or metabolic disorders such as Phenylketonuria (PKU;)
- chromosomal anamolies which can cause disorders such as Prader-Willi Syndrome, Down Syndrome, Fragile X Syndrome;
- exposure of the uterus to teratogens such as chemicals, metals, radiation, infectious disease, and alcohol, tobacco and other drugs;
- maternal conditions such as gestational diabetes, malnutrition, physical trauma; and
- neural tube defects in the early stages of an embryo's development.

Disorders occurring during birth, after birth or during childhood that can cause disorders resulting in developmental disabilities include: 15

- oxygen deprivation;
- low birth weight;
- > preterm birth;

<sup>&</sup>lt;sup>11</sup> Larson, et. al, p. 245.

<sup>&</sup>lt;sup>12</sup> Gosden; See also Graziano, pp. 124-125.

<sup>&</sup>lt;sup>13</sup> Larson, et. al, pp. 247-248.

<sup>&</sup>lt;sup>14</sup> Graziano, Chapters 4 through 7.

<sup>&</sup>lt;sup>15</sup> Graziano, Chapter 8.

- infectious disease with high fever;
- intentional or unintentional injuries (traumatic brain injury;)
- malnutrition.

Several conditions that cause developmental disabilities have become rare in recent years as preventative measures have been identified through research and implemented on a widespread basis. <sup>16</sup>

## What is a Developmental Delay?

Developmental delay refers to a child acquiring skills and abilities more slowly than the norm for their age. Delays may be present in one or more functional areas such as motor skills and language. The presence of a developmental delay does not necessarily mean that a child has or will have a developmental disability. Some delays are temporary in nature.

Vision and hearing impairments in young children are strongly correlated with developmental delays. Vision impairment changes how a child understands and functions in the world. Impaired vision can affect a child's cognitive, emotional, neurological, and physical development by possibly limiting the range of experiences and the kinds of information a child is exposed to. Nearly two-thirds of children with vision impairment also have one or more other developmental disabilities, such as mental retardation, cerebral palsy, hearing loss, or epilepsy. <sup>17</sup>

Approximately 30% of children who are deaf or hard of hearing also have one or more other developmental disabilities, such as mental retardation, cerebral palsy, vision impairment, or epilepsy. Hearing loss can affect a child's ability to learn both to speak and to understand spoken language. This is especially true if the child is born with a hearing loss or loses his or her hearing before two years of age.<sup>18</sup>

<sup>&</sup>lt;sup>16</sup> Newborn Screening to Prevent Mental Retardation, The Arc, available on-line at: <a href="http://www.thearc.org/faqs/nwbrnqa.html">http://www.thearc.org/faqs/nwbrnqa.html</a>; See also Graziano, pp. 96-100 (PKU), pp. 104-105 (Hypothyroidism), pp. 126-127 (Neural Tube Defects,) p. 171 (Rh Incompatibility.) See also American Academy of Pediatrics, Committee on Genetics (1999.) Folic Acid for the Prevention of Neural Tube Defects, *Pediatrics*, 104, pp. 325-327, available on-line at: <a href="http://www.aap.oirg/policy/re9834.html">http://www.aap.oirg/policy/re9834.html</a>.

What is Vision Impairment? Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, available on-line at: <a href="http://www.cdc.gov/ncbddd/ddvi.htm">http://www.cdc.gov/ncbddd/ddvi.htm</a>.

<sup>&</sup>lt;sup>18</sup> What is Hearing Loss? Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, available on-line at: <a href="http://www.cdc.gov/ncbddd/dd/ddvi.htm">http://www.cdc.gov/ncbddd/dd/ddvi.htm</a>.

Early intervention can help families better meet the needs of their child with a developmental delay and may reduce the future need for services and supports. Washington State receives federal funding for early intervention services under Part C of the Individuals with Disabilities Education Act (IDEA.)<sup>19</sup> These services are coordinated by the Infant Toddler Early Intervention Program (ITEIP,) which is part of DDD. ITEIP provides a statewide system of early intervention services. The State uses the following definition of developmental delay to determine eligibility for these federally funded services:

Developmental Delay - A child has a developmental delay if she/he is experiencing a 1.5 standard deviation or 25% of chronological age delay in one or more developmental areas or has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.<sup>20</sup>

## How many people have developmental disabilities?

There is no national or state registry or recording or reporting standards for developmental disabilities. The prevalence rate of developmental disabilities, as defined in federal law, has been estimated at 11.3 people per thousand (1.13%) of the non-institutionalized United States population. This estimate is based on data from the 1994/1995 National Health Interview Survey conducted by the National Center for Health Statistics, part of the Centers for Disease Control and Prevention in the United States Department of Health and Human Services. The prevalence rate of developmental disabilities, as defined in federal law, has also been estimated by age groups:

Table 1: Estimated Percent of U.S. Population with Developmental Disabilities by Age Group

Age Group	Percent of Non-institutionalized U.S. Population
0-5	3.8%
6-17	1.9%
18+	0.6%

Source: Larson, et. al, p. 244

<sup>&</sup>lt;sup>19</sup> 20 United States Code 1431 to 1445.

<sup>&</sup>lt;sup>20</sup> Washington State's Federally Approved Plan for Federal Fiscal Year 2004 for ITEIP, Section III (A.) For detailed definition, see Washington State's Federally Approved Plan for Federal Fiscal Year 2004 for ITEIP, Section IV (A), available on-line at: <a href="http://www1.dshs.wa.gov/word/adsa/iteip">http://www1.dshs.wa.gov/word/adsa/iteip</a>.

<sup>&</sup>lt;sup>21</sup> Larson, et. al, p. 247.

The estimated number of non-institutionalized King County residents who have a developmental disability as defined in federal law is 20,062 persons, based on the 1.13% prevalence rate.<sup>22</sup> This estimate is likely lower than the actual number due to the increase in the prevalence of Autism Spectrum Disorders during the past ten years (see footnote 6.) The estimated 20,062 people with developmental disabilities in King County is more than double the 9,236 people with developmental disabilities who were enrolled in DDD on January 31, 2005.

## What are the functional limitations experienced by people with developmental disabilities?

Developmental disabilities affect individual functioning in a variety of ways including:

Mobility: Some people are unable to walk;

Communication: Some people are unable to speak or to speak clearly;

Cognitive: Some people have difficulty learning or processing

information;

Some people have difficulty interacting with others. Social:

Table 2 shows the estimated percent of individuals with developmental disabilities age 18 and above who have each of the functional limitations specified in the federal definition of developmental disabilities:

Table 2: Functional Limitations

Functional Limitation	Percent of persons with developmental disabilities 18 and above
Learning	34.1%
Self-direction	65.7%
Language	39.6%
Personal Care	9.9%
Mobility	14.4%
Economic self- sufficiency	97.3%
Independent activities of daily living	59.6%

Source: Larson, et. al, pp. 243, 246.

Revision Date: 7/1/05

<sup>&</sup>lt;sup>22</sup> Prevalence rate of .0113 multiplied by April 1, 2004, King County population estimate of 1,788,300 from State Office of Financial Management adjusted to 1,775,405 to reflect .7% noninstitutionalized population (Based on 2000 Census: King County institutionalized population of 12,525 divided by total population of 1,737,034 yields .7% estimated institutionalized population.)

Functional limitations in any one of these areas can pose a serious obstacle to independent living and participation in activities at home, school and work.

## What are supports?

Supports are resources and strategies that enhance the abilities of an individual with a developmental disability to more fully participate in community life.<sup>23</sup> Supports narrow the gap between the competencies required in the physical and social environment and the individual's current skill level.

The main types of supports are:

- assistance provided by other people;
- assistive technology; and
- accessibility modifications to buildings.

What is assistive technology?

Assistive Technology is any item, piece of equipment, product or system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of persons with disabilities.<sup>24</sup>

Natural supports are those provided by family, friends, neighbors and other people who are part of the community in which an individual with a developmental disability lives and works. Examples of natural supports include:

- assisting with personal care tasks such as dressing or grooming;
- assisting with independent living skills such as balancing a checkbook, shopping for groceries, or finding a bus stop;
- providing a ride to work or a bus stop; and
- installing ramps and grab bars in a home, church or work place so they can be accessed by an individual with mobility limitations.

Service based supports are those provided by teachers, job coaches, therapists, health care providers and other professionals or paraprofessionals who are paid for their assistance. Examples of service based supports include:

- physical therapy, occupational therapy and language and speech therapy;
- job development and job coaching;

Page 15

Revision Date: 7/1/05

<sup>&</sup>lt;sup>23</sup> Based on definition in Luckasson, J, et. al (2002.) Mental Retardation: Definition, Classification and Systems of Supports, 10<sup>th</sup> Edition, Washington, D.C.: American Association on Mental Retardation, Chapter 9.

<sup>&</sup>lt;sup>24</sup> Developmental Disabilities Assistance and Bill of Rights Act of 2000, PL 106-402, Section 102 (3,) codified at 42 United States Code 15002 (3.)

- assisting with personal care tasks or independent living skills; and
- assistive technology (e.g., hearing aids)

Family supports are resources and strategies, including paid services that assist a family to care for an individual with developmental disabilities. Examples of family supports include:

- respite care (which offers an occasional break from care giving;)
- professional consultation by therapists (physical, occupational, speech, behavioral;)
- specialized equipment (lifts, diapers, specialized clothing;)
- support groups (parents, siblings, fathers groups.)

The type and intensity of supports needed by individuals with developmental disabilities varies according to each individual's functional limitations. The need for supports and their intensity changes over an individual's lifespan. The intensity of supports can range as follows.<sup>25</sup>

Intermittent: Supports provided on an "as needed" basis. An example is

assisting an individual to find a new job if they lose their job.

Limited: Supports provided over a limited time frame such as during the

transition from school to work.

Extensive: Supports needed on a daily basis but not constantly, such as

assistance with dressing, bathing and grooming.

Pervasive: Supports needed on a daily and constant basis which may include

life sustaining measures, such as line of sight supervision.

Supports are identified through individual planning processes that emphasize the unique abilities, needs and priorities of individuals with developmental disabilities. These planning processes include but are not limited to:

Individualized Family Service Plan (IFSP) for children ages birth to three
An IFSP is prepared by a Family Resource Coordinator in collaboration with a
family and early intervention professionals at the time their child begins to receive
early intervention services. Family Resource Coordinators (FRC) assist families
in assessing child and family needs, identifying their priorities, finding resources
to match those priorities and accessing and coordinating services the child or

2

<sup>&</sup>lt;sup>25</sup> Based on information in "Disability Awareness Begins with You" an information sheet on mental retardation, Pierce County Parent Coalition, available online at: http://www.pc2online.org/DA/Mental%5FRetardation%2Epdf.

family may need. The IFSP guides early intervention services for children with disabilities and their families and is updated every six months or more frequently if appropriate. It contains information about the services necessary to facilitate a child's development and enhance the family's capacity to enhance their child's development. Through the IFSP process, family members and service providers work as a team to plan, implement, and evaluate services tailored to the family's unique concerns, priorities, and resources.

The IDEA requires the IFSP to be in writing and include:<sup>26</sup>

- 1. The child's present levels of physical development, cognitive development, communication development, social or emotional development, and adaptive development;
- 2. The family's resources, priorities, and concerns relating to enhancing the development of their child with a disability;
- 3. The major outcomes to be achieved for the child and the family; the criteria, procedures, and timelines used to determine progress; and whether modifications or revisions of the outcomes or services are necessary;
- 4. Specific early intervention services necessary to meet the unique needs of the child and the family, including the frequency, intensity, and the method of delivery;
- 5. The natural environments in which services will be provided, including justification of the extent, if any, to which the services will not be provided in a natural environment;
- 6. The projected dates for initiation of services and their anticipated duration;
- 7. The name of the service provider who will be responsible for implementing the plan and coordinating with other agencies and persons; and
- 8. Steps to support the child's transition to preschool or other appropriate services

Federal regulations require that services needed by a child but not funded under IDEA Part C, such as medical services, also be described in the IFSP, along with the funding sources for those services. The statute allows parents to be charged for some services. If a family will be charged, this should be noted in the IFSP.<sup>27</sup>

http://www1.dshs.wa.gov/word/adsa/iteip.

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<sup>&</sup>lt;sup>26</sup> 20 United States Code 1436 (d;) 34 Code of Federal Regulations 303.344.

<sup>&</sup>lt;sup>27</sup> Bruder, M. (2000.) The Individual Family Service Plan, ERIC Clearinghouse on Disabilities and Gifted Education, Council for Exceptional Children, available on-line at: http://www.eric.ed.gov (ERIC #ED449634;) see also Washington State's Federally Approved Plan for Federal Fiscal Year 2004 for ITEIP, Section IV (G) available on-line at:

## What are "natural environments?"

Natural environments means settings that are natural or normal for the child's age peers who have no disabilities. These environments are home, neighborhood, or community settings in which children without disabilities participate.<sup>28</sup>

Individual Education Plan (IEP) for children and young adults ages 3 through 20 The IEP is prepared by a team from the student's school district consisting of a general education teacher, a special education teacher, a school district representative who is qualified to provide or supervise specially designed instruction, individuals who can interpret evaluation results, the student's parents and other individuals that the parents or the district invites. Students are invited to participate in IEP meetings starting at age 14, sometimes earlier.

The IEP is prepared when a child with a disability enters the public school system and is updated annually. Children with disabilities may enter the public school system and receive special preschool education as young as age three although some children's disabilities are not recognized until elementary school or middle school.

The IEP commits the school district to provide special education, accommodations and other services to enable the student to receive a free appropriate public education. The IEP includes:<sup>29</sup>

- 1. The student's present level of educational performance, including how the student's disability affects the student's involvement and progress in the general curriculum.
- A statement of measurable annual goals, including benchmarks or shortterm objectives that describe how the student will be involved in and progress in the general curriculum.
- 3. Special education and any necessary related services including how much and how long services are expected to last, where and who will provide them so the student can advance toward the annual goals.

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Washington State's Federally Approved Plan for Federal Fiscal Year 2004 for ITEIP, Section III (A.) See also Guidelines for Implementing Early Intervention Services in Natural Environments, Washington State ITEIP, October 2001, available on-line at: http://www1.dshs.gov/word/adsa/iteip/NEnviro.doc.

<sup>&</sup>lt;sup>29</sup> 20 United States Code 1414 (d); 34 Code of Federal Regulations 300.340 to 300.350; Washington Administrative Code 392-172-160.

- 4. A statement of how the student will participate in State or district assessments, with or without modifications or other accommodations. The IEP includes an explanation if the IEP team determines that participation in assessments is not appropriate, as well as a description of how the student will be assessed.
- 5. A statement of how parents will be informed of their child's progress toward annual goals and the extent to which progress is sufficient to enable the student to achieve goals by the end of the year.
- 6. Beginning at age 14, or earlier if appropriate, the IEP must include a statement of transition service needs. Beginning at age 16, or earlier if appropriate, the IEP must specify transition services that will be provided. Beginning at least at age 17, the student must be informed of rights that will transfer to the student on reaching the age of majority and the IEP should reflect this information.
- 7. When needed, the IEP also lists strategies that the students needs to receive a free appropriate public education, including positive behavioral interventions, the use of Braille, assistive technology, accommodations, or other aids and services that enable the student to receive a free appropriate public education.<sup>30</sup>

Service Plans for individuals of all ages who are enrolled in DDD An Individual Service Plan (ISP) is defined in State law (RCW 71A.18.010) as a plan that identifies the needs of a person for services and determines what services will be in the best interests of the person and will meet the person's needs. State regulations (WAC 388-825-050) require the development of the ISP to involve DDD staff, the person, their parent or guardian, advocate and representatives of the agency or facility who is, or will be, primarily responsible for the implementation of specific provisions of the plan. The ISP is a planning document and does not guarantee the authorization or delivery of services.

The ISP is called a Plan of Care for individuals enrolled in one of the four Medicaid HCBS waivers (described in Chapter 3.) Individuals enrolled in DDD who are receiving Medicaid Personal Care services must also have a Medicaid Personal Care Plan. Individuals enrolled in DDD who are receiving residential services must also have an Individual Habilitation Plan.

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<sup>&</sup>lt;sup>30</sup> Family/Educator Guide to Washington's Special Education Services, Washington State Office of the Superintendent of Public Instruction, Revised July 2002, pp. 23-26, available on-line at: http://www.k12.wa.us/SpecialEd/pubdocs/family\_educator\_guide/family\_educator\_guide\_2000.doc.

## **Chapter 3 - Supports Provided by DDD and KCDDD**

#### DDD

The State's role in the developmental disabilities service system is mandated by the State Constitution and Revised Code of Washington (RCW.)

Washington State Constitution, Article XIII, State Institutions Section I, Educational, reformatory, and penal institutions; those for the benefit of youth who are blind or deaf or otherwise disabled; for persons who are mentally ill or developmentally disabled; and such other institutions as the public good may require, shall be fostered and supported by the state, subject to such regulations as may be provided by law. The regents, trustees, or commissioners of all such institutions existing at the time of the adoption of this Constitution, and of such as shall thereafter be established by law, shall be appointed by the governor, by and with the advice and consent of the senate; and upon all nominations made by the governor, the question shall be taken by ayes and notes, and entered upon the journal. [AMENDMENT 83, 1988 House Joint Resolution No. 4231, p 1553. Approved November 8, 1988.]

## RCW 71A.10.015 Declaration of policy.

The legislature recognizes the capacity of all persons, including those with developmental disabilities, to be personally and socially productive. The legislature further recognizes the state's obligation to provide aid to persons with developmental disabilities through a uniform, coordinated system of services to enable them to achieve a greater measure of independence and fulfillment and to enjoy all rights and privileges under the Constitution and laws of the United States and the state of Washington. [1988 c 176 § 101.]

The State's role is carried out by the Department of Social and Health Services through DDD. DDD administers services on a regional basis. King County and Region 4 DDD are geographically the same. DDD is responsible for determining eligibility and authorizing paid services.

Eligibility requirements for enrollment of an individual as a client of DDD are set forth in State regulations (Washington Administrative Code 388-823, effective July 5, 2005.)

Services for Washington State residents with developmental disabilities are not an entitlement. Services are limited based on the availability of funds. The State's funding for services comes from a combination of federal grants, State funds appropriated by the Legislature and the federal Medicaid program. Under Medicaid, the Federal Government and state governments both contribute to the

cost of health services for lower income individuals. The specific eligibility requirements and types of services covered are defined in a State plan.

Since the early 1980's, the Federal Government has allowed states to use Medicaid to pay for Home and Community Based Services (HCBS) for people with developmental disabilities as an alternative to institutionalization. The Federal Government's approval for this practice is set forth in a "waiver" agreement between the State and the Federal agency responsible for Medicaid. Washington State's Medicaid HCBS waiver, known as the Community Alternatives Program waiver, was replaced with the following four new waiver programs effective April 1, 2004: Basic, Basic Plus, Core, and Community Protection. Each waiver program provides a "package" of services and supports when Medicaid state plan services and other supports are not sufficient. 31 Enrollment in the four waiver programs is limited.

DDD currently provides the following services:

## Case Management

All individuals who are enrolled in DDD are assigned a case manager. Case managers assess the needs of individuals and their families, determine whether an individual is eligible for State paid services, and connect them to available DDD and other available services and supports. Case managers authorize payment for state-funded services including those that are provided by KCDDD.

## Medicaid Personal Care (MPC)

MPC provides personal care assistance for Medicaid eligible persons with a functional disability. This service is provided in the person's own home by an individual or homecare agency provider, or in licensed contracted adult family homes and boarding homes. MPC is also provided to eligible children who live at home or in a foster home.

## Residential Services

Licensed Settings: In community-based licensed residential programs, such as group homes, Institutions for the Mentally Retarded, adult family homes and foster care, the provider owns or leases the facility. Room and board expenses are included in the rate paid by DDD and residents participate toward their cost of care. To provide services in a variety of smaller licensed settings located in the community, DDD contracts with providers or coordinates with other DSHS divisions. All licensed settings offer 24-hour supervision. All residential settings with five or more tenants require licensing.

King County Plan for Developmental Disabilities Services Revision Date: 7/1/05

<sup>&</sup>lt;sup>31</sup> For a summary of the services provided under each of the waiver programs, see DDD's Waiver Plan Fact Sheet available on line at: http://www1.dshs.wa.gov/word/adsa/ddd/waiverFacts.doc.

Supported Living Services: DDD contracts with and certifies individuals and agencies to provide support to persons who live in their own homes in the community. Supports may vary from a few hours per month to 24 hours of one-to-one support per day. Clients pay for their own rent, food, and other personal expenses; DDD pays for supports. DDD also offers certified supported living services provided by State employees through the State Operated Living Alternative Program.

## Residential Habilitation Centers (RHC)

State employees provide intensive services in five state operated residential facilities for individuals needing skill development or a high level of nursing care. There is one RHC in King County (Fircrest School,) which is located in the City of Shoreline.

## Family Support

Family support services provide a variety of individual and community services, including respite care and therapies, to assist families in caring for their family member in their home.

## Dental Program

The Dental Program provides oral health education for people with developmental disabilities of all ages. The program is offered through contracts with dental hygienists.

#### Mental Health

DDD and Mental Health collaborate to provide an array of mental health services and supports to individuals who are dually diagnosed with developmental disabilities and mental health disorders.

#### Voluntary Placement Foster Care Program

Voluntary placement offers supports to a child in a licensed placement outside the family home. This usually happens when parents are unable to meet the extraordinary needs of their children at home.

## Medically Intensive Home Care Program

The Medically Intensive Program provides in-home private duty nursing services and medical equipment to children age 17 or younger who have medically intensive needs (e.g., ventilator dependent, tracheotomy care) that require continuous skilled care and can be provided safely in the home.

#### KCDDD

Washington State's policy is to provide services for people with developmental disabilities on a state and local basis.

RCW 71A.14.010, Coordinated and comprehensive state and local program. The legislative policy to provide a coordinated and comprehensive state and local program of services for persons with developmental disability is expressed in RCW 71A.12.010. [1988 c 176 § 301.]

RCW 71A.12.010, State and local program -- Coordination -- Continuum. It is declared to be the policy of the state to authorize the secretary to develop and coordinate state services for persons with developmental disabilities; to encourage research and staff training for state and local personnel working with persons with developmental disabilities; and to cooperate with communities to encourage the establishment and development of services to persons with developmental disabilities through locally administered and locally controlled programs. The complexities of developmental disabilities require the services of many state departments as well as those of the community. Services should be planned and provided as a part of a continuum. A pattern of facilities and services should be established, within appropriations designated for this purpose, which is sufficiently complete to meet the needs of each person with a developmental disability regardless of age or degree of handicap, and at each stage of the person's development [1988 c 176 § 201.]

RCW 71.20.110 mandates that counties collect a property tax and dedicate these funds to provide community services for persons with developmental disabilities or mental health services.

RCW 71.14.020 enables counties to appoint a developmental disability board to plan services for persons with developmental disabilities and to provide directly or indirectly a continuum of care and services to persons with developmental disabilities within the county or counties served by the board.

RCW 71A.14.030 directs the State to work with the counties who apply for state funds to coordinate and provide local services for persons with developmental disabilities and their families.

King County's role is carried out by the County's Department of Community and Human Services through KCDDD. KCDDD currently provides the following day program services:

### Early Intervention

Early intervention services are provided for children birth to three years of age who have a developmental delay or disability. Family Resource Coordinators (FRC) assist families in assessing child and family needs, identifying their priorities, finding resources to match those priorities and accessing and coordinating services the child or family may need. Early intervention services are provided by contracted agencies and other community based service providers through government, public and private funding sources, including insurance. The County's Early Intervention System is described in more detail at the end of this Chapter.

## Behavior Support Project

Crisis response and in-home behavioral intervention support, family counseling, planning and training is available to parents and caregivers of children and youth ages 3-17 who are enrolled with DDD. Services are comprehensive and short-term, four to eight weeks.

## Family Support Community Service Grants

Grants are awarded to organizations to assist children and adults with developmental disabilities living in King County in their families' homes. The grants support programs that encourage integration into the community through community resource development, information and education initiatives, parents helping parents, provider staff development and addressing the diverse needs of Native Americans, communities of color and limited or non-English speaking groups.

#### Information and Assistance

Assists individuals to understand and navigate the developmental disability service system either in person, on the phone, or on-line.

### Community Outreach Team

Staff assists families from diverse communities, including African American, Asian/Pacific Islander, and Latin American communities, to navigate the developmental disabilities service system and obtain information and supports on behalf of their family member. Staff encourage individuals with developmental disabilities and their families to participate on advisory boards and committees to ensure they have a voice within the developmental disability system. Information and training is provided to organizations on cultural competence in service delivery.

#### Parent-to-Parent

Parent-to-Parent provides information, resources, training, advocacy skill development and emotional support to families of children with developmental disabilities. Parent volunteers receive training, are encouraged to participate in their local community and are matched with other parents. Through these efforts parents have a better understanding of their child's disability and the emotional impact to the family. There are regularly scheduled meetings, internet support groups and family get-togethers. The program ensures culturally competent service acquisition and support for families from communities of color who face unique challenges when their child has a disability.

#### Leadership Project

This project is designed to assist adults with developmental disabilities to become effective leaders and influence the developmental disabilities system. Participants are recruited from all geographic areas of King County. Support and skill development needs are identified for each participant. Identified support may include, but are not limited to, assistance with transportation, stipends,

internships and other accommodations. Skill development includes teaching participants to communicate their needs assertively, to understand existing laws and benefits learn and practice decision making and problem solving skills and the responsibilities of citizenship and any other areas as identified by the participant. At least 60% of the participants must live independently in the community and/or with their families or other relatives.

## Parent Coalition/Parent Training

The King County Parent Coalition is a group of parents and family members who advocate for a better future in the community for people with developmental disabilities. The Coalition provides training on topics of interest to participants as well as opportunities for participating in legislative advocacy. The Coalition hosts an annual Fall Forum for Legislators in conjunction with the King County Board for Developmental Disabilities.

## Housing Referral and Information

Assists people to obtain Section 8 housing vouchers from public housing authorities, provides information on housing resources and advocates for development of affordable housing opportunities for people with developmental disabilities.

## Community Access

Community Access services are for adults enrolled in DDD who are age 62 and over who have retired. Services assist individuals to participate in activities, events and organizations in the community in ways similar to others of retirement age.

#### Social and Recreational Activities

Grants are awarded to organizations to provide opportunities for individuals with developmental disabilities to access the same social and recreational activities that non-disabled individuals use in the community.

### **Employment Services**

Pathway to Individual Employment: Assists individuals to develop individual pathway to employment plans and reach employment goals according to his/her preference and interest in integrated settings. Note: This service is also called Person-to-Person.

Individual Employment: Facilitates an individual with a developmental disability working for a community business. Self-employment may also be an option. A provider agency helps the person find a job and provides training and support. People earn at least minimum wage and receive benefits.

Group Supported Employment: Enables three or more people (up to eight individuals) with disabilities to work in a group in the community. Some groups are located at a single site such as a restaurant or a store, others move from site to site such as custodial or grounds-keeping work. Employees may earn less

than minimum wage.

Prevocational Services (formerly Specialized Industries Employment:) Designed specifically for people with developmental disabilities. The work typically consists of piece work (e.g., putting pieces of a product together or packaging items.) People are employed in a large group workshop setting. Employees generally earn wages based on their productivity.

Employment Resource Coordination: Services include providing information on how paid employment impacts Social Security benefits, analyzing benefits, and helping people identify resources to pay for employment supports.

Transition Project: Young adults ages 21-22 who are exiting their high school transition program without funding for job supports (i.e., from DVR or DDD) may use up to \$5,000 to pay for supports needed to obtain paid employment. Once employed, individuals may continue to finance job supports through a Social Security Administration Work Incentive Program.

King County School to Work Project (formerly known as the Work Training Project:) Provides work experience opportunities for young adults who are preparing to exit their high school transition program.

#### Program Development/Technical Assistance

Services include assistance to providers in implementing effective and evidence-based practices such as positive behavior solutions and coordination of training events, conferences, seminars, and technical assistance to individuals and families and other developmental disabilities stakeholder groups throughout King County. In addition, support and technical assistance is available on-site at WorkSource Renton to assist individuals with developmental disabilities, their families, transition programs and others associated with employment for people with developmental disabilities, to fully access available resources, training, programs and employment opportunities available.

### **KCDDD Budget**

State funds from DDD pay for:

Early Intervention

Community Access

Individual Employment, Group Supported Employment and Prevocational Services

Pathway to Individual Employment (also called Person-to-Person)

Federal Funds passed through State DDD (provided under Federal Individuals with Disabilities Education Act) pay for:

Early Intervention

King County funds from mental health/developmental disabilities millage (a dedicated property tax) pay for:

Employment Resource Coordination

Information and Assistance

Parent to Parent

Community Outreach Team

Leadership Project

Parent Coalition/Parent Training

Housing Referral and Information

Transition Project

King County School to Work Project

State/County joint funding partnerships pay for:

**Behavioral Support Project** 

Family Support Community Services Grants

Social and Recreational Activities

Program Development/Technical Assistance

See Tables 3 - 5 for more details on KCDDD's budget.

Table 3: KCDDD Revenue Summary 2001-2005

Revenue Source	2001 Actual	2002 Actual	2003 Actual	2004 Actual	2005 Budget
State	\$13,191,931	\$13,502,818	\$13,505,281	\$13,872,662	\$15,750,685
Federal	\$1,466,110	\$1,193,012	\$1,288,375	\$1,373,665	\$1,327,225
County	\$2,140,193	\$2,216,771	\$1,320,853	\$2,363,626	\$2,436,869
Total	\$16,798,234	\$16,912,601	\$16,114,509	\$17,609,953	\$19,514,779

Table 4: KCDDD Expenditure Summary 2001-2004

Revenue Source	2001 Actual	2002 Actual	2003 Actual	2004 Actual	2005 Budget
State	\$13,119,705	\$13,730,554	\$13,275,412	\$13,907,486	\$15,750,685
Federal	\$1,475,769	\$1,503,274	\$1,286,557	\$1,385,328	\$1,327,225
County	\$2,607,601	\$2,134,348	\$2,057,264	\$1,590,451	\$2,866,305
Total	\$17,203,075	\$17,368,176	\$16,619,233	\$16,883,265	\$19,944,215
Change in					
County Fund					
Balance	(\$404,841)	(\$455,575)	(\$504,724)	\$726,688	(\$429,436)

## Notes on Table 3 and Table 4:

- 1. The revenue summary shows a large increase in State funds in 2005.

  This is due to the State now including certain funds in the County's funding contract that were previously deposited in individual client accounts.
- 2. Expenditure figures can exceed revenue figures when KCDDD supplements budgeted revenues with County funds accumulated from prior years (fund balance.)

Table 5: KCDDD Expenditure Detail for 2003-2005

Support	2003 Actual Expenditures	2004 Actual Expenditures	2005 Planned Expenditures
Early Intervention	\$2,741,887	\$2,895,531	\$2,831,923
Behavioral Support Project	\$258,679	\$227,698	\$250,000
Family Support Community Service Grants	\$223,597	\$162,491	\$146,154
Information, Referral, Advocacy & Outreach Activities*	\$498,002	\$654,878	\$657,854
Housing Referral and Information	\$67,380	\$73,506	\$80,000
Community Access	\$1,741,547	\$1,769,638	\$1,859,792
Social & Recreational Activities	\$62,253	\$60,000	\$65,000

Support	2003 Actual Expenditures	2004 Actual Expenditures	2005 Planned Expenditures
Employment Services			
Pathway to Individual Employment (Person to Person)	\$1,804,093	\$2,260,072	\$2,534,718
Individual Employment	\$3,357,790	\$3,367,543	\$4,135,764
Group Supported Employment	\$768,475	\$734,677	\$845,180
Prevocational Services (formerly Specialized Industries Employment)	\$2,135,461	\$1,788,247	\$2,213,160
Employment Resource Coordination	\$186,592	\$174,054	\$188,532
Transition Project	0	\$58,242	\$220,000
King County School to Work Project	\$124,827	\$110,764	\$120,000
Subtotal Employment Services:	\$8,252,411	\$8,324,593	\$9,917,354
Program Development/ Technical Assistance	\$496,484	\$547,103	\$1,345,472
Administration	\$2,152,166	\$1,998,821	\$2,450,666
TOTAL	\$16,619,233	\$16,883,265	\$19,944,215

<sup>\*</sup>Information, Referral, Advocacy & Outreach Activities include: Information and Assistance, Community Outreach Team, Parent-to-Parent, Leadership Project, and Parent Coalition/Parent Training.

## The Early Intervention System in King County

KCDDD's Early Intervention System continually seeks opportunities for collaboration with other programs and agencies that serve typically developing children and/or specific populations. At the KCDDD level, most of these collaborations focus on County-wide activities or planning processes. While subcontracted Early Intervention Providers attend and participate in community or sub-regional activities in an effort to ensure representation of Early Intervention providers in activities which encourage or enhance inter-system coordination. Examples of activities which are occurring and are representative of system coordination include:

 Sub-contractor participation at Seattle, North and East FACES (Family and Child Early Support) meetings;

- KCDDD staff participation on the prevention/early intervention action team of SOAR, helping children reach for the sky. SOAR is a community partnership to improve the success of children and youth in life and in school. The prevention/early intervention action team is focused on ensuring that families can access high quality, affordable and culturally competent services to help assess their children's development and address problems as early as possible.
- KCDDD staff participation in Neighborhood House's Head Start Plan development;
  - Participation on the Children's Health Access Advisory Committee;
  - Participation with United Way of King County's Children's Initiative/Success by Six and the Welcome Baby Project; and

These efforts have created several opportunities for collaborations and these partnerships positively impact on the Early Intervention system. Many more collaborations occur directly between the providers and other service systems. For example, at least two providers have contracts with Early Head Start to provide services for their Early Head Start children in need of Early Intervention. The partnerships and collaborations will be maintained and increased.

Childfind and public awareness activities are currently sub-contracted with the Washington Health Foundation–Community Health Access Program (CHAP.) CHAP is the central point for distribution of materials and provision of information. CHAP staff also participates in various community efforts and activities at which opportunities exist for developmental screenings or information sharing. Participation in such events help families become familiar with early intervention and provide an opportunity to ask questions about development. CHAP staff may be called upon to attend meetings of organizations where there might be shared clients. Provider agencies also play an important role in Childfind in King County through referral networks with pediatricians, hospitals, and schools and by having a visible presence in their communities.

Overall, King County's Childfind activities are effective in that we currently serve approximately 1.9% of the Birth to Three population. However, feedback from families and agencies continues to express concern that some families or subsets of families may not be referred in a timely manner or may have difficulty navigating the referral system.

The current service system seems to work well once a family is connected with a provider or with the central point of entry, CHAP. Referrals are made by a broad variety of people or organizations. Providers have relationships with the medical community where referrals to specific providers are made directly by the physician, or by many other community organizations. Conversations with

Families and other feedback revealed that some families had concerns about their own child's development but did not know initially where to turn for assistance. While there is widespread distribution of materials, there seems to be the need for an increased presence so that it is widely known around the county where to call for assistance in entering our system.

Once connected with CHAP or with a direct referral, families can be linked to a Family Resource Coordinator (FRC.) However, over the last few years families from the certain geographic areas of the County periodically find providers at capacity and have to be referred back to CHAP for referrals to more distant providers.

King County contracts with 15 community organizations to provide direct early intervention services, and each of those providers staff their programs to ensure adequate service coordination. While each agency deploys their staff differently and in a way which best reflects their service model and needs, according to the State Infant Toddler Early Intervention Program's (ITEIP) data system there are approximately 57 staff registered as FRCs in King County.

In addition to the provider-employed FRCs, KCDDD contracts with CHAP to provide independent FRC services. If a family wants independent FRC services they may receive them from one of the CHAP FRCs. In addition, CHAP FRCs are the designated service coordinators for families with children who are deaf or hard of hearing. This is intended to provide increased opportunities for families to receive a wide range of information about the complex issue of service/education models for these children in order to assist them in making a decision which will best fit with their family's priorities and routines.

Most families express high degrees of satisfaction with the direct services that they receive including FRC services. Strengths of our current system include:

- Established referral patterns from physicians, hospitals, and other primary referral sources assist most families to achieve access to an appropriate early intervention services provider in their area in a reasonable amount of time.
- The numbers of children ages birth through two years of age and their families who access these services have increased steadily for the past five years.

Initial evaluations and assessments are coordinated within the geographic service area FRCs assist families in identifying their concerns and priorities related to their child's development and gather information about evaluations and assessments that the child and family has already had outside the early intervention system. The FRC then assists the family in scheduling the remaining evaluations/assessments with qualified staff employed by the early intervention provider system.

Early intervention services are provided in home and community settings where children without disabilities participate. Evidence based practices in working with

infants and toddlers with disabilities identify that effective practices provide supports within the context of families' lives, support child and family participation in every day life and focus on naturally occurring learning opportunities, rather than contrived specialized instruction. Evidence also demonstrates that children's mastery of functional skills occur through high-frequency, naturally occurring activities in a variety of settings that are consistent with their family and community life.<sup>32</sup>

The King County early intervention system is characterized by a high level of involvement of the provider network that offers a variety of service options and locations. As part of the initial and ongoing assessment and IFSP processes, families identify their individual family routines and activities. They also consider community activities in which they would like to participate but might find challenging due to their child's delay or disability. In the IFSP, the family and their early intervention providers identify the home and community settings in which the early intervention services will be provided in order to meet the IFSP outcomes. If an outcome can not be met within a home or community setting in which children without disabilities participate, the IFSP team includes a justification in the IFSP as to why the services can only be provided in a segregated setting.

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<sup>&</sup>lt;sup>32</sup> Edelman L. University of Colorado Health Sciences Center, Enhancing Services in Natural Environments, presentation at U.S. Department of Education, Office of Special Education Programs, National Early Childhood Conference, Washington D.C., February 2005.

# Chapter 4 - Issues

KCDDD staff and the Board for Developmental Disabilities analyzed data from numerous sources and identified five key issues for KCDDD to focus on during the next four year period. These issues are not in priority order:

Issue #1: Many working age adults with developmental disabilities do not have access to day program/employment supports due to

inadequate public funding.

Issue #2: Many individuals with developmental disabilities, and their families,

need supports that are not widely available.

Issue #3: Individuals with developmental disabilities, and their families, need

> supports that are provided in a culturally competent manner and that follow effective and evidence-based practices on a consistent

basis.

Issue #4: Individuals with developmental disabilities, and their families, need

accurate information about what supports are available and how to

access them.

Issue #5: Individuals with developmental disabilities are not routinely included

in or served by the activities of public and private organizations in

King County.

Issue #1: Many working age adults with developmental disabilities do

not have access to day program/employment supports due to

inadequate public funding.

Day Program/Employment supports for working age adults

State funding is insufficient to cover the cost of day programs/employment supports for the approximately 4,000 working age adults enrolled in DDD Region 4. Currently, about 41% of enrolled working age adults are participating in day programs. See Table 6 below.

Under the State's Working Age Adult Policy, 33 which was effective July 1, 2004, and must be fully implemented by July 1, 2006, individuals enrolled in DDD who are between the ages of 21 and 61 must be either employed or on a pathway to employment in order to receive any type of State paid supports including day program/employment supports.

Revision Date: 7/1/05

<sup>&</sup>lt;sup>33</sup> DDD Policy 4.11, County Services for Working Age Adults, available on line at: http://www1.dshs.wa.gov/pdf/adsa/ddd/policies/policv4.11 07 04.pdf.

When the four new waivers were implemented in 2004, many individuals who were enrolled in the former single waiver program were moved into slots in one of the new waivers. The number of slots in the new waivers is limited by State funding and very few slots are available for individuals to move into each year. Currently, 1,618 of working age adults are on a waiver (this is 41% of the total number of working age adults.)

DDD and KCDDD are legally obligated to meet the day program/employment support needs of individuals with developmental disabilities who are on the waivers. There are approximately 666 working age adults who are on a waiver but not currently receiving day program/employment supports. If additional funding is not appropriated by the State Legislature to pay for day program/employment supports for these individuals, then DDD and KCDDD may need to discontinue paying for supports for some or all of the 672 working age adults who are currently receiving supports but are not on a waiver.

There is currently no State funding available to pay for day program/employment supports for the 1,670 working age adults who are not currently participating and are not on a waiver.

State funding is also insufficient to cover the cost of day program/employment supports for some individuals who need more intensive services. The amount of funding available for supports to individuals on a waiver is limited.

Table 6: Individuals Ages 21-61 Enrolled in DDD Region 4 by Waiver Status and Participation in Day Programs/Employment Supports on January 31, 2005

		Percent of Total Ages 21-61
On Waiver and in day program	952	24.0%
On Waiver Not in day program	666	16.8%
Total on Waiver	1618	
Not on Waiver and in day program	672	17.0%
Not on Waiver and not in day program	1670	42.2%
Total Not on Waiver	2342	
TOTAL AGES 21-61	3960	100%
Total Ages 21-61 in day program	1624	41%
Total Ages 21-61 not in day program	2336	59%

Source: DDD CCDB

Employment supports for young adults transitioning from school to work Approximately 150 young adults age 21 with developmental disabilities exit high school transition programs in King County each year. The State Legislature has appropriated funding to enable transition students to obtain employment and other supports from DDD since 1988 (with the exception of 2003.) The amount falls far short of the need. King County received transition funding for only 26 out of 290 eligible individuals in the 2003-05 State budget.

While the State Division of Vocational Rehabilitation (DVR) provides short-term employment supports for young adults with developmental disabilities who are transitioning from school to work, these individuals may be placed a wait list due to DVR's Order of Selection process.

# Issue #2: Many individuals with developmental disabilities, and their families, need supports that are not widely available.

Parents and other stakeholders who participated in the planning process identified a need to increase the availability of the following supports that are not widely available:

## Supports for School-Age Youth

Children and youth with developmental disabilities need supports to participate in social and recreational activities with typically developing peers.

Youth with developmental disabilities need assistance to establish a personal vision for their future.<sup>34</sup>

## **Aging Caregivers**

There is a significant number of aging caregivers who have adult children with developmental disabilities living at home. As of January 2005, 420 individuals enrolled in DDD Region 4 were age 35 and above and living in their parent's home. Of this group, only 105 were on a waiver and therefore eligible for State paid services.

Families have many concerns about the future well-being of their sons and daughters when they are no longer able to provide care at home. Adults with developmental disabilities and their aging caregivers need assistance with transition planning and information on financial, legal, and residential options.

<sup>&</sup>lt;sup>34</sup> Data from the Center for Change in Transition Services, Seattle University, indicates that King County students with developmental disabilities have poorer post-school outcomes compared to students in the balance of Washington State. See Appendix C, p. 24 for data

Table 7: Individuals Age 35+ Enrolled in Region 4 DDD and Living in Parent's Home on January 31, 2005

Age Group	Number on Waiver	Number Not on Waiver	Total Number
35 – 44	60	216	276
45 – 54	42	75	117
55+	3	24	27
Total	105	315	420

Source: DDD CCDB

## Private Supports

Adults with developmental disabilities who are not able to obtain State paid day program/employment supports need opportunities to develop and retain adaptive skills and participate in their community. Families also need the respite that day programs and employment supports offer.

Families that want to privately arrange day programs/employment supports for their family member with developmental disabilities need technical assistance to plan and implement activities.

Issue #3: Individuals with developmental disabilities, and their families, need supports that are provided in a culturally competent manner and that follow effective and evidence-based practices on a consistent basis.

## Cultural Competence

Beliefs, values and cultural norms vary widely within the County. According to the 2000 Census, 27% of King County residents are from communities of color. There were 9,236 individuals in King County who were enrolled in the State DDD system as of January 31, 2005. There is a higher proportion of individuals from communities of color enrolled in Region 4 DDD than in the County population at large. <sup>35</sup>

King County has significant numbers of refugees and immigrants, many of whom do not speak English as a first language. Approximately 17% of King County residents are foreign born and approximately 19% of King County residents over the age of 5 speak a language other than English at home.<sup>36</sup> School district data

 $<sup>^{\</sup>rm 35}$  See Appendix B, p. 3, Table 3; See also Appendix B, p. 10, Table 15.

<sup>&</sup>lt;sup>36</sup> U.S. Census Bureau, American Community Survey, 2003 Data Profile, King County, Table 2, Selected Social Characteristics, Region of Birth of Foreign Born and Language Spoken at Home, available on-line at: <a href="http://www.census.gov/acs">http://www.census.gov/acs</a>.

on languages indicate that large immigrant populations are in South King County communities.<sup>37</sup> It is imperative that supports and services for individuals with developmental disabilities and their families are delivered in a culturally competent manner.

What are culturally competent services?

The term `culturally competent,' used with respect to services, supports, or other assistance, means services, supports, or other assistance that is conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports, or other assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved.<sup>38</sup>

<sup>&</sup>lt;sup>37</sup> 2004 King County Annual Growth Report, p. 8, available on-line at: <a href="http://www.metrokc.gov/budget/agr/agr04">http://www.metrokc.gov/budget/agr/agr04</a>.

<sup>&</sup>lt;sup>38</sup> Developmental Disabilities Assistance and Bill of Rights Act of 2000, PL 106-402, Section 102 (7), codified at 42 United States Code 15002 (7.)

Table 8: Enrollment in Region 4 DDD by Age Group, Ethnicity and Hispanic Origin on January 31, 2005

Age	African	% of	Amer.	%	Asian/	%	White	%	Other	%	Not	%	Total	%
Group	Amer.	all in	Ind &		Pacific						Reported			Hispanic
		age	Alaska		Islander									
		group	Native											
0-2	78	6.8%	18	1.6%	106	9.2%	601	52.4%	78	6.8%	266	23.2%	1147	
Hispanic	1	0.9%	0	0.0%	4	3.7%	18	16.5%	10	9.2%	76	69.7%	109	9.5%
3-20	432	11.2%	112	2.9%	477	12.3%	2087	53.9%	303	7.8%	462	11.9%	3873	
Hispanic	9	3.2%	3	1.1%	22	7.9%	40	14.3%	166	59.3%	40	14.3%	280	7.2%
21-61	372	9.4%	76	1.9%	260	6.6%	3083	77.9%	67	1.7%	102	2.6%	3960	
Hispanic	2	2.9%	3	4.3%	3	4.3%	21	30.4%	32	46.4%	8	11.6%	69	1.7%
62+	10	3.9%	2	0.8%	5	2.0%	238	93.0%	0	0.0%	1	0.4%	256	
Hispanic	0				0		0		0		0			0.0%
TOTAL	892	9.7%	208	2.3%	848	9.2%	6009	65.1%	448	4.9%	831	9.0%	9236	
Hispanic	12	2.6%	6	1.3%	29	6.3%	79	17.2%	208	45.4%	124	27.1%	458	5.0%

Source: DDD CCDB

Table 9: Enrollment in KCDDD Day Programs by Age Group and Ethnicity on January 31, 2005

Age	African-	% of	Amer.	%	Asian/	%	White	%	Other	%	Not	%	Total
Group	American	all in	Ind. &		Pacific						Reported		
		age	Alaska		Islander								
		group	Native										
0-2	49	6.5%	8	1.1%	67	8.9%	408	54.3%	41	5.5%	179	23.8%	752
21-61	128	7.9%	27	1.7%	81	5.0%	1333	82.1%	19	1.2%	36	2.2%	1624
62+	4	6.0%	0	0.0%	0	0.0%	63	94.0%	0	0.0%	0	0.0%	67
TOTAL	181	7.4%	35	1.4%	148	6.1%	1804	73.8%	60	2.5%	215	8.8%	2443

Source: DDD CCDB

Providers vary in their practices, which impacts the quality and types of supports available to individuals with developmental disabilities. There is not a shared understanding among stakeholders of what effective- and evidence based practices are and how they contribute to quality of life for individuals with developmental disabilities and their families.

## School District Participation in Funding Early Intervention

IDEA Part C requires the State to ensure that all children who need Early Intervention services are able to access services; however, Federal appropriations for IDEA Part C have been static while the number of children enrolled continues to increase each year. This has resulted in a decline in the amount of funding available to providers for each child. School districts are able to access federal special education funds for Early Intervention services, but are not required to do so. Currently only 10 of the 19 school districts in King County are participating in funding Early Intervention services, which means providers that serve families in 9 school districts have a much higher fundraising burden and are less able to pay for training or other improvements, including those relating to cultural competence and effective and evidence-based practices.

# Issue #4: Individuals with developmental disabilities, and their families, need accurate information about what supports are available and how to access them.

Although KCDDD has funded Information and Assistance, the Parent Coalition/Parent Training and the Parent-to-Parent program for many years, parents, advocates and other stakeholders who participated in the planning process identified improved access to accurate information as a critical issue.

Some families may need individual assistance to find information and access supports, particularly senior families, immigrant/refugee families, very low-income families, and families with caretakers who are ill or have disabilities.

In addition, many young people leave school at age 18 but their parents are unaware that employment and other day program services are not available for young adults 18-21 years of age. It is important that individuals and parents are provided with this information and information regarding their options during transition planning.

# Issue #5: Individuals with developmental disabilities are not routinely included in or served by the activities of public and private organizations in King County.

People with developmental disabilities live in communities throughout King County. They should be able to fully participate in their communities and access services that are available to all individuals. The larger community is not aware of how developmental disabilities affect individuals and families and how community members can promote the inclusion of people with developmental disabilities.

# **Chapter 5 - Goals, Objectives, and Strategies**

KCDDD will address the key issues described in Chapter 4 by pursuing the goals identified below. One goal is stated for each issue. Goals, objectives and strategies are not listed in priority order. KCDDD will use available resources to carry out the objectives and strategies identified under each goal during the plan period. The objectives and strategies will also provide a framework for measuring performance. The particular strategies that will be implemented each year will be determined in conjunction with developing KCDDD's annual budget and work program.

What are goals, objectives and strategies?

- Goals are results we would like to see progress on at the end of the four-year plan period.
- Objectives are results we would like to achieve in the short term that will help us move toward meeting a goal.
- > Strategies are actions that we will take to accomplish an objective.

# Issue #1: Many working age adults with developmental disabilities do not have access to day program/employment supports due to inadequate public funding.

Goal for Issue #1: All working age adults with developmental disabilities have access to day

program/employment supports.

Objective 1: Increase the number of individuals who access employment supports.

#### Strategies for Objective 1

- a. Continue to advocate for increased State funding to provide employment supports for working age adults not on a waiver.
- b. Seek grant funding to increase access to employment supports for working age adults who are not on a waiver.
- c. Expand Employment Resource Coordination and the Transition Project to assist working age adults not on a waiver to pay for employment supports.
- d. Explore feasibility of providing technical assistance to families that want to privately arrange day program/employment supports for working age adult family members.

# Issue #2: Many individuals with developmental disabilities, and their families, need supports that are not widely available.

Goal for Issue #2: School age youth with developmental disabilities as well as adults with

developmental disabilities living in the community can access supports that are not currently widely available regardless of whether they are on a

waiver.

Objective 2A: Increase the number of school age youth who define and meet their post-

school outcomes.

## Strategies for Objective 2A

- a. Expand the King County School to Work Project to offer work experience to more school age youth.
- b. Expand the Employment Resources Coordination outreach to provide more parents and school age youth with information and resources for transition planning.
- c. Target Program Development/Technical Assistance to train parents and school personnel in person-centered planning in order to assist school age youth in developing a personal vision for their adult life and preparing for employment.
- d. Work with school districts and other service systems such as DVR to provide information to individuals and families to encourage them to begin transition planning as early as possible and prepare for school to work transition.
- e. Recommendation for DDD Region 4: Encourage case resource managers to participate in IEP meetings.

Objective 2B: Increase the number of aging caregivers who receive individual assistance

with transition/permanency planning for their adult family members with

developmental disabilities who live at home.

### Strategies for Objective 2B

Collaborate with the Area Agency on Aging and DDD Region 4 to identify families who need individual assistance and resources to provide individual assistance.

Objective 2C: Increase housing opportunities for individuals with developmental

disabilities.

### Strategies for Objective 2C

a. Continue to fund KCDDD's Housing Innovations for Persons with Developmental Disabilities program that leverages city, county and state capital dollars to set-aside units in multi-family housing developments specifically for individuals with developmental disabilities and families who have a child with developmental disabilities.

King County Plan for Developmental Disabilities Services

Page 41

Revision Date: 7/1/05

- b. Continue to explore the feasibility of developing a homeownership program for persons with developmental disabilities in King County.
- c. Continue to support efforts that prevent or reduce homelessness among people with developmental disabilities.

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Issue #3: Individuals with developmental disabilities, and their families, need supports that are provided in a culturally competent manner and that follow effective and evidence-based practices on a consistent basis.

Goal for Issue #3: Providers provide supports in a culturally competent manner and use

effective and evidence-based practices on a consistent basis.

Objective 3A: Increase the capacity of providers to deliver services in a culturally

competent manner and to use effective and evidence-based practices on a

consistent basis.

## Strategies for Objective 3

- a. Collaborate with families, advocates and other stakeholders to develop a shared knowledge base around cultural competence and recommend actions for evaluating and building provider capacity.
- Collaborate with families, advocates and other stakeholders to develop a shared knowledge base around effective- and evidence-based practices and recommend actions for evaluating and building provider capacity.
- c. Explore whether contracts for services should more clearly identify agency service models, to ensure implementation of culturally competent and effective/evidence-based practices.

Issue #4: Individuals with developmental disabilities, and their families, need accurate information about what supports are available and how to access them.

Goal for Issue #4: Accurate information about available supports and how to access them is

available to individuals with developmental disabilities and their families.

Objective 4A: Improve access to information about supports for individuals with

developmental disabilities and their families.

## Strategies for Objective 4

a. Collaborate with DDD Region 4, schools, providers and families to analyze needs, identify gaps and develop a regional communication plan.

Issue #5: Individuals with developmental disabilities are not routinely included in or served by the activities of public and private organizations in King County.

Goal for Issue #5: Individuals with developmental disabilities are able to participate in

recreational, volunteer, civic and other community activities and can access

generic human services.

Objective 5A: Increase the inclusion of people with developmental disabilities in generic

recreational, volunteer and civic opportunities.

## Strategies for Objective 5A

a. Continue to assist organizations that provide social and recreational opportunities to make their programs accessible for people individuals with developmental disabilities.

b. Develop methods for recognizing organizations that include people with developmental disabilities in their activities.

Objective 5B: Increase access to generic human services for people with developmental

disabilities.

## Strategies for Objective 5B

a. Provide training and technical assistance to assist human service providers to develop their capacity to serve people with developmental disabilities.

King County Plan for Developmental Disabilities Services Revision Date: 7/1/05